

**Response ID BHLF-5VS1-NC81-9**

Submitted to **1. Summary survey**

Submitted on **2019-11-05 15:12:26**

**1. What Scotland needs to do****1 What do you think about the ideas in this section?**

I have mixed feelings about the ideas

**Why do you think that?:**

At Down's Syndrome Scotland (DSS) we welcome the review of learning disability and autism in the Mental Health Act. We believe that the proposed

recommendations have the potential for positive impact on the lives of people with Down's syndrome (Ds) and their families. Our primary focus is on issues

relating to learning disability although we recognise that people with Ds could also be autistic.

We agree that the current Mental Health Act does not serve the interests of people with a learning disability and needs to change. We agree that the law should

comply with the European Convention on Human Rights (ECHR) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

However, we question whether the new 'positive rights' law proposed in the review would meet this standard. Article 12 of the UNCRPD states that there should

be no discrimination under the law on the basis of disability. The current Mental Health Act allows people to be subject to detention and compulsory treatment on

the basis of their disability, therefore does not comply. We have some concerns about the definition of learning disability and the proposed criteria for

decision-making in relation to compulsory detention and treatment which allow the possibility of people continuing to have their rights denied on the basis of their disability.

**2 Could these ideas be made better?**

Yes

**How could these ideas be made better?:**

As the recommendations of the stage 3 review conclude that the current legislation is not good enough, we believe that there should be new legislation to protect

the rights of people who have a learning disability. This legislation should be underpinned by human rights as set out by the ECHR and the UNCRPD. We think

that incorporation into Scots law of the UNCRPD, could be done through a similar process to the incorporation of the UNCRC (Children's rights legislation) and that this would provide a legal basis to support, promote and protect the rights of people with a learning disability and autistic people.

## **2. How we understand autism, learning disability and mental health**

### **1 What do you think about the ideas in this section?**

Not Answered

#### **Why do you think that?:**

We agree that learning disability should not be defined as a 'mental disorder'.

We believe there should be a shift from the concept of assessing whether or not a person has legal capacity, to a process of supported decision-making.

Substitute decision-making after a person has been deemed to lack capacity, represents a denial of rights on the basis of disability. In our view this represents a breach of article 12 of the UNCRPD

### **2 Could these ideas be made better?**

Yes

#### **How could these ideas be made better?:**

The proposed definition of learning disability as occurring when a person with intellectual impairment experiences stress, distress or serious limitation, suggests

that the 'disability' is embodied in the mental state of the person, rather than external factors such as environmental and attitudinal barriers. The inference is that it

may be legitimate to treat the stress or distress, the manifestations of disability, in order to resolve the situation, this feels more aligned to the medical rather than the social model of disability.

## **3. Support for decision making**

### **1 What do you think about the ideas in this section?**

I like the ideas

#### **Why do you think that?:**

We agree that a system of supported decision making including a statement of rights, will and preferences would help to protect the rights of people with a learning disability.

We support the increased role of advocacy but recognise that this would need increased resource to fund, staff and deliver the service to everyone who needs/wants it.

We agree that research is needed to better understand current practice around psychotropic medication for people with a learning disability and particularly for those who do not have a mental illness.

## **2 Could these ideas be made better?**

Yes

### **How could these ideas be made better?:**

The role of family/unpaid carers and decision supporters must be acknowledged. The individual with a learning disability is likely to be a family member and their desired outcomes may be closely tied to their family situation. Approaches such as Family Group Conferencing and Circles of Support could be useful in the supported decision-making process.

The requirement for a human rights assessment before using a psychological intervention such as Positive Behavioural Support (PBS) is problematic in that many professionals and family carers may have learned and may regularly apply the principles of PBS in their day-to day interactions with the person they support.

## **4. Support, care and treatment**

### **1 What do you think about the ideas in this section?**

I like the ideas

### **Why do you think that?:**

We strongly agree with the recommendation that people with a learning disability should have access to regular health checks. This is particularly important for people with Down's syndrome who have lower life expectancy than other groups and often experience health complications from undetected or untreated, but preventable, conditions.

We agree that children's rights must be protected by law and support the full incorporation of the UNCRC into Scots law

We agree that there should be a duty on public authorities to consult with disabled people's organisations.

### **2 Could these ideas be made better?**

Yes

**How could these ideas be made better?:**

Using the Equality and Human Rights Impact Assessment in planning services would help to protect rights. However, we have doubts about the suggestion that the Mental Welfare Commission should set standards and monitor Health and Social Care Partnership services for people with learning disabilities. The paradigm shift that is required to change the culture around learning disability so that people are seen as equal citizens with equal rights rather than as either having a disorder requiring treatment or having lesser rights on the basis of their impairment, requires a set of standards not grounded in mental health. Perhaps this duty would be better placed within a new Commission for Learning Disability.

**5. Where support, care and treatment happens**

**1 What do you think about the ideas in this section?**

I have mixed feelings about the ideas

**Why do you think that?:**

We agree that there should be an end to compulsory detention and treatment in hospital for people with a learning disability but we are unsure about how the proposed Secure Support Centres would work. If a person is being treated for a mental illness that requires admission to a psychiatric hospital, the hospital should be required to make any necessary adaptations. If the person does not have a mental illness then we must be very careful about the basis for admitting them to a secure centre.

**2 Could these ideas be made better?**

Yes

**How could these ideas be made better?:**

We agree that there is a need to support independent living but are wary of the suggestion of 'specialist housing in groups' as this seems against the principles of inclusion and community membership. We believe that people with a learning disability should be supported to live in the community of their choice, with family or others they choose to live with, rather than in specialist housing provision

**6. How professionals make decisions**

**1 What do you think about the ideas in this section?**

I have mixed feelings about the ideas

**Why do you think that?:**

We support fuller implementation of the UNCRPD as law and would urge that all necessary steps be taken to end detention and compulsory treatment on the basis of disability as soon as possible. However, we recognise that any changes to the law must not result in the loss of those services, support and protections that are valued and needed.

The section on criteria for compulsory detention seems to replace 'mental disorder' with 'disability' as defined in the review and therefore continues to allow discrimination on the basis of disability.

We agree that there should be more awareness training for all professionals involved in providing support for people with learning disabilities.

**2 Could these ideas be made better?**

Yes

**How could these ideas be made better?:**

Alongside the Human Rights Assessment process which sets out how professionals might make decisions, it would be good to see more plans for how individuals will be supported to make their own decisions and how people would be involved in the human rights assessment process.

The use of the Mental Health Officer to complete the human rights assessment again equates learning disability with a mental health condition, perhaps there is another role that could fulfil this function.

The requirement for 'special regard' for the rights, will and preferences of people with a learning disability may not be strong or clear enough to protect those rights, a stronger position as reported in the Essex Autonomy project quoted in the review, is that of 'rebuttable presumption'

The discussion on the Approved Clinician and other roles seems to suggest that medical expertise is the highest authority in making judgements about appropriate care and support for people with a learning disability. This does not support the required culture shift towards a social model, viewing people with a learning disability as equal citizens with equal rights.

**7. How decisions are monitored**

**1 What do you think about the ideas in this section?**

I have mixed feelings about the ideas

**Why do you think that?:**

We strongly agree that people with a learning disability and autistic people should be involved in developing, implementing and monitoring law and services and that disabled people's organisations should have a role in making this happen.

We support the shift to a human rights approach, where all citizens have equal rights. We recognise that extra legislation may be required to reinforce the changes required.

**2 Could these ideas be made better?**

Yes

**How could these ideas be made better?:**

We suggest that a new Commission for Learning Disability may be needed to promote and protect the rights of people with a learning disability. We believe that this could replace some of the functions currently held by the Mental Welfare Commission but could have a remit to protect people's rights as equal citizens rather than as people requiring support for a mental health condition.

The role of the Mental Health Tribunal should be restricted to cases where a person has been diagnosed with a mental illness or has been subject to compulsory treatment or detention under the Mental Health Act. Cases concerning access to services or support could be considered by a learning disability commission

**8.Offenders**

**1 What do you think about the ideas in this section?**

I like the ideas

**Why do you think that?:**

We agree that there should be equal treatment in law for offenders and that appropriate adjustments should be made for anyone who needs them, including offenders, witnesses and victims. Intermediaries would be a useful support and the consideration of intellectual or autistic impairment as a mitigating factor would also be appropriate in some cases.

**2 Could these ideas be made better?**

Not Answered

**How could these ideas be made better?:**

## **9. Where support, care and treatment happens for offenders**

### **1 What do you think about the ideas in this section?**

I like the ideas

#### **Why do you think that?:**

We support the emphasis on rehabilitation in the community and the principle that people with a learning disability should not be detained any longer than other offenders. We recognise the need for equal protections and for training for staff involved in the criminal justice system.

### **2 Could these ideas be made better?**

Not Answered

#### **How could these ideas be made better?:**

## **10. What this means for the law**

### **1 What do you think about the ideas in this section?**

I have mixed feelings about the ideas

#### **Why do you think that?:**

We agree that the rights of people with learning disability and autistic people should be protected by law, but we are unsure about the benefits of the new law

proposed by the review. We feel that where people have a mental illness, they should be treated under the mental health act in the same way as other citizens.

Where they do not have a mental illness, they should not be subject to compulsory treatment and should have their rights protected as set out in the UNCRPD.

The Mental Health Act should equally respect the rights of people with mental illness whether or not they have a learning disability or are autistic, a separate law

to cover mental health for certain groups seems to go against the equality principle.

The suggestion of having one new law for intellectual impairment and autism which would make it possible to limit rights, in the absence of mental illness, when

people are experiencing autistic disability or intellectual disability, would not represent equal treatment under the law and would breach the UNCRPD in the same

way as the current Mental Health Act.

### **2 Could these ideas be made better?**

Not Answered

**How could these ideas be made better?:**

We feel that the way to fully protect the rights of people with learning disabilities and autistic people is to have the UNCRPD is incorporated into law. A

programme of implementation would be required to ensure that the principles of the UNCRPD are reflected in all areas of practice and a learning disability

commission could have a role in protecting human rights.

**About you**

**1 What is your name?**

**Name:**

Vivien Jayne

**2 Are you taking part as an individual person, as a professional or as a group of people?**

A Group

**3 Do any of these apply to you?**

None of the above

**4 If you are taking part as a professional, what is your profession?**

**Profession:**

Policy Officer

**5 If you are taking part as a group, what is the name of your group?**

**name of group:**

Down's Syndrome Scotland

**6 Do you live in Scotland?**

Yes

**7 Do you want us to publish your response?**

Yes please publish my response anonymously

**If you want to say anything else at all please say it here:**